

Trip Report: Malawi
20 July to 27 July 2008
Palliative Care Assessment of PACT sub-grantees

Report date: 21 August 2008

Consultant: Jenny Hunt

Consultancy period: (14 days)

20-27 July 2008 (8 days) in Malawi for data collection and site visits

6 days at home (Zimbabwe) to complete documentation/ reports etc.

The report will summarise the scope of work and objectives of the consultancy. A brief overview of activities and contacts made will lead into a presentation of specific issues relating to the assessment. Recommendations will be made concerning next steps to be taken to scale up palliative care of PACT partners in Malawi.

Acronyms and abbreviations

APCA	African Palliative Care Association
BCC	Behaviour Change Communication
CBO	Community Based Organisation
CCAP	Church of Central Africa Presbyterian
CHAM	Christian Health Association Malawi
CHBC	Community Home Based Care
COPRED	Community Partnership for Relief and Development
DHO	District Health Office
HBC	Home based care
KS	Kaposi's Sarcoma
MAICC	Mponela AIDS Information and Counselling Centre
M&E	Monitoring and Evaluation
MoH	Ministry of Health
NAPHAM	National Association of People Living with HIV/AIDS in Malawi
NGO	Non-governmental Organization
OVC	Orphans and Vulnerable children
PACAM	Palliative Care Association of Malawi
PICT	Provider-Initiated Counseling and Testing
PLWHA	People Living with HIV/AIDS
PMTCT	Prevention of Mother to Child Transmission
SDA	Seventh Day Adventist
VCT	Voluntary Counselling and Testing

Objectives of the consultancy

The goal of this consultancy is to establish the current status of palliative care delivery amongst 10 PACT partners that offer HBC/palliative care and make recommendations for further improvement of palliative care services. The objectives are:

1. To establish the nature of the identified organisations and their current understanding of palliative care
2. To explore the range of services and components delivered and the models used by the various organisations
3. To identify the current strength and gaps for palliative care delivery

4. To make practical recommendations for the strengthening of palliative care services among PACT partners.

Methodology

A combination of methods was used to review existing documentation, systems, referral patterns, drug availability and supervision. Training manuals and documentation were reviewed. The consultant undertook most interviews and discussions in central and southern districts. PACAM staff conducted interviews and discussions with organizations in the northern region and those in other regions who had not been available to the consultant. Interviewer-led questionnaires using APCA questionnaires (refer to Appendices 1-4) were completed with 5 managers, 4 health workers, 2 volunteers and 3 patients. In-depth discussions were held with a further 5 managers (often in a group with other providers), 4 professional health providers (often nurses or clinical officers in a group with other personnel), 3 volunteer care providers and 1 patient. This method was chosen for groups of respondents where an individual in-depth interview was inappropriate, or when time was limited, or when it was deemed more suitable. Discussion was based upon the questions used in the questionnaires but was less formatted and responsive to replies. Field notes of all discussions were collected. Data was analysed by consolidating themes and patterns. These are discussed in detail in the section below pertaining to specific issues relating to the consultancy.

Providers of services were rated according to the supportive and palliative care classification tool provided by APCA.

Caveat

Interviews and discussions were undertaken by 3 people due to the time frame of the consultancy. As a result different interview styles may introduce variations in data quality and consistency.

Outcomes

This assessment report will provide an overview of the status of palliative care provided by 10 PACT sub-grantees in Malawi. Objectives 1 and 2 above will be discussed per each organization. Objectives 3 and 4 will be discussed according to themes that were identified in the course of the assessment with relevance to each organisation. Recommendations will be made concerning opportunities for introducing and expanding palliative care to those programmes.

Background¹

Despite the lack of good epidemiological data, experiences of health care workers have led to the development of palliative care services for Malawian patients and their families, 85% of which live in rural areas. Many people in Malawi with incurable illness are discharged from hospital to the care of their families. Little is known about the care they receive or how they die. The first dedicated palliative care team in Malawi started in the department of paediatrics in 2001 at the country's only teaching hospital, Queen Elizabeth Central Hospital in Blantyre. Children admitted to the oncology ward were recognised as needing holistic support (including adequate pain relief) alongside their chemotherapy. This paediatric oncology service is the only dedicated cancer service in the country. There are no

¹ Adapted from a report by Dr Maya Jane Bates MBChB, MRCGP, Secretary, Palliative Care Association of Malawi

radiotherapy services, and adult chemotherapy, when available, is prohibitively expensive. With the combined effects of HIV/AIDS and poverty, Malawi ranks 165th out of 177 countries on the Human Development Index.² The per capita total expenditure on health is one of the lowest in sub-Saharan Africa.³ As cancer care expands the challenge is to integrate palliative care, a relative newcomer to the health system, throughout the health care system – at both hospital and community level – in the context of poor staffing and erratic drug supplies. The WHO public health model of palliative care delivery is invaluable in Malawi, both for guiding development and reviewing progress. Home-based care constitutes a significant part of current palliative care provision and is well established in Malawi with significant government support.

Recent developments in palliative care in Malawi⁴

The Palliative Care Association of Malawi (PACAM) was established in 2005 and has formed strong partnerships with key stakeholders. The Ministry of Health sent representatives to recent regional events organised by the African Palliative Care Association (APCA), which has helped consolidate these partnerships. National policy on palliative care is lacking and is crucial for extending implementation of services. However, significant steps have been made in palliative care education and drug availability. For a full appraisal refer to Wright and Clark (2006).

A number of health professionals have undertaken distance learning courses in Uganda, South Africa and Kenya which have deepened the local knowledge base in palliative medicine. In 2007, the Ministry of Health Nursing Section collaborated with PACAM to standardise and accredit a local 5-day introductory palliative care training course for health care workers. Next steps include integrating palliative care modules into the curricula of government and mission hospital pre-service training institutions.

Throughout the health sector, drug availability is a difficult issue and this is no different in palliative care. There is limited understanding of the cost and suitability of opiate preparations, though morphine (either as oral morphine liquid or slow release tablets) has been available at limited sites since 2004. Laxative stock-outs have sometimes hampered best practice. Early in 2008 PACAM collaborated with the Ministry of Health Pharmacy Department to address some of these issues. Key policy makers and representatives from provider institutions met to discuss suitable import quotas, systems for procurement, reporting and distribution. They recommended that oral morphine liquid and slow release tablets should be made available at all health institutions in Malawi. The challenge of translating these achievements into improved access to palliative services for those most in need is one that the national association and its members will be addressing.

Through a partnership between PACAM and the African Palliative Care Association (APCA) funded through PACT Malawi, PACAM is charged with the role of providing technical

² United Nations Development Programme. *Human Development Report 2005 New York*. 2005

³ Zere E, Moeti M, Kiringa J, Mwase T, Kataika E Equity in health and healthcare in Malawi: analysis of trends BMC Public Health. 2007; 7: 78.

⁴ Adapted from a report by Dr Maya Jane Bates MBChB, MRCP, Secretary, Palliative Care Association of Malawi

assistance to stakeholders who are interested in scaling up their palliative care services. This needs assessment was requested by PACT Malawi to inform the strengthening of the palliative care services provided by its partner organisations, and ultimately improve the quality of life of services to beneficiaries. All the PACT sub grantees receive funding for palliative care except Namwera AIDS Coordinating Committee (NACC). Some of the organizations receive funding for all HBC/Palliative care activities while others get funding only for trainings and/or operations.

Activities

Prior to the consultant's visit PACAM contacted all relevant PACT partners to arrange visits. In the time available for the consultancy 7 partners were visited in central and southern regions. The remaining 3 partners which are in the northern region were visited by PACAM without the APCA consultant. The same methodology applied.

The 10 PACT partners are:

- I. Mponela AIDS Information and Counselling Centre (MAICC)
- II. National Association of People Living with HIV/AIDS in Malawi (NAPHAM)
- III. Nkhoma Synod
- IV. Lighthouse
- V. Namwera AIDS Coordinating Committee (NACC)
- VI. Malamulo SDA Hospital
- VII. Community Partnership for Relief and Development (COPRED)
- VIII. Ekwendeni CCAP Hospital
- IX. Tutulane AIDS Organization
- X. Lusubilo Orphan Care

Person seen/position	Organisation	Contact details
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Erick de Jonge (CEO) Patrick Makono	Church of Central Africa Presbyterian (CCAP) Nkhoma Synod	h.c.c.dejonge@gmail.com
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Volunteer, Sailesi Bamusi (Secretary, Executive Committee)	Namwera AIDS Coordinating Committee (NACC)	michaelalidi@yahoo.com namweraaids@sdp.org.mw
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Specific issues relating to the consultancy

Objectives:

1. To establish the nature of the identified organisations and their current understanding of palliative care.
2. To explore the range of services and components delivered and the models used by the various organisations

For ease of analysis these will be rearranged as

Objective 1: to establish the nature of the identified organizations, the range of services and components delivered by which models.

Objective 2: to establish the organizations' current understanding of palliative care.

Objective 1: Nature of the organizations, range of services delivered and models used

o Mponela AIDS Information and Counselling Centre (MAICC)

MAICC has 5 core programmes: VCT, community HBC, OVC care, youth programme and food security/nutrition. They have a staff of 6 field officers, 1 care and support coordinator (medical assistant) and 1 HBC manager. This is an integrated health care model with referrals and links between the programmes.

The organization gets rapid testing kits from DHO and Save the Children (USAID). All ART is free to patients and is distributed through the DHO.

The HBC programme is administered by 508 volunteers. The criteria for accepting clients into the programme are based on national HBC guidelines ie. sick for longer than 3 months.

The organization has access to Mponela rural hospital, 2 CHAM hospitals, Dowa district hospital and 4 of the 7 health centres in the district.

Referrals work well from the HBC programme to the hospitals but not from the hospital to the organisation. When a patient is discharged from hospital to their community the organisation is not notified. Internal referrals between programmes work efficiently to assure total care for patients, from testing to care and support.

- **National Association of People Living with HIV/AIDS in Malawi (NAPHAM)**

This NGO has the following programmes:

- Outreach in terms of information, education and teaching about HIV in schools and work places using a message of prevention for positives and condom use
- Counselling
- Drop-in centre
- HBC
- Resource centre
- Group therapy for adults and children (play for 5-15 year olds, provided with HIV information and ARV information).

It was possible to only interview a nurse/trainer from this organization who was unable to provide further organizational details. In the HBC programme volunteers receive national HBC training and visit clients regularly in their homes. Despite repeated requests there is a lack of materials to do effective home based care eg. soap for washing clothes and the patient. Volunteers get 1000 kwacha per month and spend it mainly on soap and transport.

- **Nkhoma Synod**

The hospital comes under the health department of CCAP. This is one of 11 CCAP hospitals, offering PMTCT, VCT and HBC services. They operate 10 health centres and a HBC programme from this hospital. From here they have access to 8 government health centres and 2 Catholic health centres. The 200 bed hospital is church-owned and is part of the Christian Health Association of Malawi (CHAM). The hospital provides services for paediatric care, and mother and child health care. There is a strong focus on maternal health which is prioritised over palliative care although 4 nurses have already been trained in palliative care.

There are 900 patients receiving ART. About 50 of those are children. In the HBC programme there are 162 registered clients with an expectation of this soon rising to 200. They have access to morphine in the hospital. Patients pay fees for service, but this can be waived if necessary.

Community health includes programmes for children under 5 years, family planning, TB and HIV services.

The HBC programme is run by community volunteers, supported by community nurses. The area is divided into 12 group villages, with 20 villages in each group, managed by HBC committees.

- **Lighthouse**

The programmes run by Lighthouse include

- HIV counselling and testing (3000 per month)
- Clinic for PLWHA, clinical assessments, OI treatments, ART (6000 actively on ART; 500 are children <15), KS and cancer palliative care.
- HBC

- Capacity building in the health sector through training. Over 30% of outlets providing ART have attended a 2 week attachment here, and this was the first site to provide these services. They also contribute to national M&E data collection, including TB and AIDS registers.

At the clinic there are 10 nurses and 10 clinical assistants.

The HBC programme employs 4 HBC nurses. All HBC nurses are registered as HBC providers through the HBC national training curriculum, and all are trained in palliative care at Lighthouse. The catchment area is the city of Lilongwe. 150 patients are contacted each month (some old, some new referrals).

There are more than 500 (mainly female) volunteers although not all are active. In June 2008 there were 443 active volunteers. The criteria used to determine whether a volunteer is active is that at least 1 patient is seen that month for follow up. An active volunteer is also expected to be in contact with the nurse at least twice a month. There are 18 groups of volunteers. The nurses rotate their weekly meetings with these groups to discuss any problems and their work in general.

Role of the HBC nurse: visits the household and supplies medications as required, food supplements, bed nets and safe water.

The volunteers identify needy patients in the community and refer them to a community care supporter who is an employed member of the team. Volunteers work within their own locality. The community care supporter conducts an initial assessment and determines whether a nurse is required and if they are eligible for Lighthouse care. The nurse then does a full assessment and palliative care assessment of the patient.

- **Namwera AIDS Coordinating Committee (NACC)**

This organization is run by a Board of trustees that includes a chief, local Member of Parliament, a representative of the District AIDS Coordinating Committee (DACC) and the district commissioner. There is an Executive committee of 10 volunteers that oversee 5 technical subcommittees – youth / HBC / OVC / PLWHA / BCC. There are 21 employed members of staff including a director, M+E officer, finance officer and field supervisors. There are no health professionals employed by the organization although the volunteers work closely with the health centre nurse as she visits the volunteers weekly. Patients (mainly PLWHA) are identified by the volunteers. Volunteers keep monthly records for NACC head office. Volunteers attend a quarterly meeting for any feedback and corrections that are needed.

The volunteer interviewed indicated that out of 28 clients that he visits 26 are on ART, and he has not witnessed any non-adherence.

- **Malamulo SDA Hospital**

This is a hospital-based integrated HIV/AIDS prevention, care and support programme based in Thyolo. There are 21 health professionals, including doctors, clinical officers and nurses. There are 5 programmes:

- HBC
- Hospital-based care
- Nutrition
- Reproductive health
- VCT, PMTCT, TB services

The hospital has another clinic at Ngabu in Chikwakwa staffed by a nurse, clinical officer and volunteers.

The hospital has trained HIV primary supervisors to act as a mid-point between the volunteers and the health staff, so that simple health strategies, including the distribution of contraceptives are undertaken without increasing the load on health professionals. Volunteers are selected by their communities.

○ **Community Partnership for Relief and Development (COPRED)**

This CBO was started in 2000 and registered in 2003 and was started as a community response to general problems. The organization provides HIV prevention, care and support services.

HIV prevention: a VCT service operates twice a week and in August 2008 this will be scaled up to a daily service. They also promote condom use.

Care and support:

- HBC and care for OVC. Volunteers are trained in both areas to offer an integrated programme to PLWHA and their families
- Agriculture, natural resources and IGA. In this programme there is an effort to reinstate the spirit of helping each other by having a communal supply of food that is organised by the whole community so that children can be released from agricultural chores and be able to return to school. The whole household is viewed as the recipient of food. The organization provides pigs and goats as food security.
- OVC programme: the organization provides school bursaries, nutritional support, and operates Kids Clubs which provide relief for guardians when children are very young. Older children enjoy drawing and play and the youth have their own groups. Some volunteers are trained in memory book work through FHI and use those skills in working with OVC.

The catchment area includes 35 villages and in each village there are 10 volunteers. Only 120 volunteers are trained.

The organization receives a broad range of funding from PACT, HIVOS, Methodist Relief and Development Fund and the Egmont Trust.

○ **Ekwendeni CCAP Hospital**

This faith-based organisation is based in Mzimba district, Northern region. There are 15 programmes, each with its own coordinator. There is overlapping and cross cutting of programmes so that the services they provide are fully integrated. Various HIV related services are provided, including VCT, PICT, PMTCT and ART provision. All the programmes employ hospital staff and about 300 community volunteers. There is a palliative care programme operated by 3 key health care workers. A weekly palliative care clinic is run at the hospital and home visits are undertaken to those patients who cannot attend the clinic.

Plans are in place to employ a Monitoring and Evaluation (M&E) officer and a driver once funding approval has been given by the National Aids Commission (NAC). Approximately 50 patients receive home-based care and palliative care.

○ **Tutulane AIDS Organization**

This CBO is based in Chitipa District, Northern Region. It is managed by a Board of Trustees, a Board of Directors and 8 programme heads who oversee the following programmes:

Income Generation

Pasaka (male involvement in PMTCT)

Theatre
Youth
Home-based care
OVC
VCT
Accounts

There are 34 employed staff and approximately 347 volunteers of whom 60 are trained in home-based care. Around 75 care givers are involved in home-based care OVC work. The head of the care and support programme is a nurse.

There are three ways clients come into the care and support programme

- after testing positive they approach the programme
- they are referred from Chitipa district hospital for home-based care
- they are identified during outreach campaigns

The programme focuses on those who have confirmed HIV positive and provides care and promotes HIV testing to those who do not yet know their status. Healthy positives are kept registered and monitored so that HBC is available when needed. Approximately 4 patients living with cancer receive care but are not included in data records. The 60 trained volunteers visit approximately 300 patients in 2 traditional authorities. The limiting factors for expansion are transport and equipment.

○ **Lusubilo Orphan Care**

This Roman Catholic faith-based organization is based in Karonga District, Northern Region. There are 5 catchment areas comprising 52 villages. In each village there is a village orphan committee.

There are 33 employed members of staff, including an HIV Coordinator, M&E officer, Field Officers, Logistics officers, care-takers (care providers to orphans) and nutrition assistants. There is a clinic at the office where patients can obtain medicines from the HIV Coordinator who is a nurse. HIV education in the community is a main activity.

The HBC programme started in January 2008 and has since trained 31 home-based care volunteers, although there are 108 registered volunteers. The aim is to achieve 80 trained HBC volunteers. Trained volunteers are spread unevenly with some of the 52 villages having none at all. Appropriate clients are identified by the trained volunteers, the village orphan committees and the field officers. Many patients are taking TB treatment, have disclosed their HIV status and are chronically ill. Most of them are paralysed and bedridden. There is a perception that the demand for services outstrips capacity, and more trained volunteers are required.

Objective 2: Palliative care understanding:

○ **MAICC:**

Those interviewed admitted “the organization is confused. Palliative care used to be seen as part of HBC and now seems to stand alone. We thought it was done in health facilities by clinicians.” The care and support coordinator defined it as “care given to a patient where the illness has no cure” although she did not know until our visit that it includes pain management. The executive director was aware that pain medication should be available to the patient at home. Essential elements were cited as including access to basic medications at home, and providing nutrition and counselling to ensure the well-being of the patient.

○ **NAPHAM:**

The nurse of the organization defined palliative care as: “When one has suffered from a chronic illness and will face the end of life; where there is no hope for recovery, they should die peacefully.” When asked to list 3 activities that she would carry out as part of palliative care she listed: providing strong analgesics, physical care (bathing, feeding and symptom care) and spiritual support (conduct prayers so they don’t lose hope).

This respondent had not heard of the WHO analgesic ladder, nor the concept of total pain. She confirmed that neither she nor the volunteers talk with patients about death and dying, the future or funeral planning.

○ **Nkhoma Synod:**

This hospital and HBC organization have obtained liquid morphine from Lighthouse for the last 3 months. Before then they had some morphine tablets. A high level of staff turnover means that those in whom they have invested palliative care training, will leave and they need to start again. Of the 2 nurses and 1 clinical officer they have trained in palliative care so far 2 are about to leave. Although they manage morphine at the hospital this is done by pharmacy assistants as there is no pharmacist.

Palliative care is understood by most people in the hospital as pain control. Those interviewed confirmed that their HBC work is mainly supportive care and cannot be regarded as palliative care. Volunteers do not talk of issues such as death and dying, and do not have the skills to discuss the impact of a terminal illness with the family.

○ **Lighthouse:**

This organization has a clear vision and implementation plan for palliative care. It provides much of the palliative care training for other organizations in Malawi and is considered a centre of excellence for palliative care. Despite that however, it appears that volunteers are reluctant to perform nursing care for patients, and skills for discussing issues around death, dying and bereavement are lacking in volunteers and health workers.

○ **NACC:**

One interviewee (Secretary on the Executive Committee) confirmed he had no idea about pain control and had never heard of morphine. A volunteer who was interviewed defined palliative care as “assisting somebody who has a problem of getting sick. It is quite different from HBC because it can be done anywhere”. When asked to list 3 palliative care activities he suggested: assisting with transport, giving educational talks and comforting the patient. He acknowledged that he does not assess pain, but manages pain at present by sponging down the patient and administering Panadol. If there is an OI he refers the patient to the health facility. Pain assessment is not done according to any guidelines in either adults or children. The most common symptoms seen are skin rashes, herpes zoster, diarrhoea and malaria. The volunteer was not confident that he can treat these and always refers to the health facility. He had not heard of the WHO ladder.

A nurse from the local health centre who works closely with the NACC volunteers received palliative care training at Lighthouse for 5 days but was unclear how that had changed her approach to HBC. She was unable to provide any clear indicators for palliative care, apart from relief of pain. She is able to take limited drugs to the home (Panadol, aspirin and ibuprofen). When asked what she does if she still sees the patient in pain she replied that she gives psychological support and takes them to the hospital. The local health centre comes under Mangochi District Hospital where morphine tablets are available.

A patient who was interviewed disclosed that volunteers tell her information but do not ask her how she would like to manage her illness. No one outside the family has asked how she feels about the illness.

- **Malamulo SDA Hospital**

The clinical officer who was interviewed confirmed that palliative care should be a component of the integrated programme at the hospital, as it is a form of care offered to terminally ill patients who are chronically ill. He understands that palliative care gives patients a positive way of living, and enables them to make informed choices while remaining with their family. He believes palliative care could add value to their programme by adding food, medications, supplements for anaemia, appetite boosters and general HBC. He would like palliative care to be available to HIV and cancer patients, and those with disabilities (such as stroke) so that their quality of life improves.

A nurse who was interviewed understood palliative care to be just the same as HBC. The HIV coordinator felt that palliative care is broader in scope and can be implemented not only in a HBC setting. It also includes support groups. Those interviewed acknowledged they are currently unable to keep clients pain-free at home. Pethidine is used as a painkiller at the hospital, and morphine MST tablets are available in the ART clinic, mainly for KS patients. They see many patients in pain. They perceive people would currently choose to die at hospital as they feel they will get better pain control. When volunteers see patients with a problem they refer to the hospital through the supervision chain, but are unable to manage them at home.

- **Community Partnership for Relief and Development (COPRED)**

The staff interviewed has no idea about palliative care, and do not claim to provide it. When patients are in pain they are referred to the health centre which is about 5 kilometres away. In the far flung areas volunteers have bicycles. Near the office the ambulance transports patients.

- **Tutulane AIDS Organisation**

Those interviewed suggested palliative care was pain relief through counseling or medical interventions. There was recognition of the term but an acknowledgement that volunteers would not truly understand what palliative care means. Essential elements of palliative care included giving patients massages, lower end analgesics, and ointments. The health worker interviewed defined palliative care as “when a patient is in pain and you provide psychological support and analgesics, like Paracetamol and spiritual counseling”. She went on to describe 3 main activities as giving pain control drugs, providing spiritual counseling and providing counselling and reassurance to both patients and families”. Pain assessment is only from what the patient says and clinical examination. No pain guides are used, and the WHO analgesic ladder is unknown, as is the concept of total pain. Drugs are mainly easily accessible here, although morphine is not available and patients are referred to the health facility if they require anything other than mild pain relief. The health worker admits to her own fears about morphine: “I fear its side effects like delirium. I saw patients after surgical operation they come out from theatre with confusion”.

- **Ekwendeni CCAP Hospital**

This facility has a well established palliative care programme with several members of staff having received training, and an aim to have all staff trained in palliative care. A nurse interviewed described palliative care as “looking after someone who is sick and chronically ill at his/her home and managing problems that may arise, e.g. pain and other symptoms”.

She had knowledge of the dangerous drugs act. Another defined it as “somebody chronically ill with cancer or severe pain, bedridden, beyond control by simple care”. Essential elements of palliative care were described by those interviewed as managing pain, bathing patient, visiting and doing domestic work. The nurse was conversant with the analgesic ladder although not fully familiar with drugs at each level, and was able to identify methods of assessing pain. Not all medications are always available and the hospital has no access to morphine. She was not aware of the concept of total pain. Limited numbers of trained staff and stock-outs of medication hinder good pain management. The facility provides the full range of HIV-related medicines including ART, prophylaxis etc., but it has an irregular supply of morphine and poor funding results in stock-outs of strong analgesics such as Diclofenac. Ekwendeni’s interest in and commitment to palliative care is evidenced by their palliative care coordinator being a PACAM director.

○ **Lusubilo Orphan Care**

This organization has a somewhat developed understanding of palliative care, although knowledge around morphine was lacking. Volunteers have not received training in palliative care and palliative care has yet to be implemented into the HBC programme. Those interviewed understood palliative care to mean providing the patient with all necessary support – spiritual, nutritional, medical and material. A volunteer offered: “I heard this term during HBC training. It was mentioned but I have forgotten. I think it means taking care of a patient who doesn’t know about his condition that we should tell him the truth. But I need to revisit my notes”. The volunteer went on to suggest 3 important activities for palliative care: Be with the patient that’s very important, counseling to relieve problems, reassuring the patient. A health worker described palliative care as “a holistic approach whereby care and support is given to terminally ill patients at home or hospital. You also provide physical and spiritual support in order to relieve suffering. Morphine is one of the drugs used for pain control”. Elements of palliative care were correctly described as: psychosocial support, spiritual support and medical care. This health worker has received 10 days of training in HIV and palliative care provided at the Baptist Church in Salima by trainers from Uganda. She knew that pain was categorized by different levels but did not use any pain scale. The WHO analgesic ladder was well understood, although she had not heard of the concept of total pain. This interviewee admitted to concerns over the addictive qualities of morphine. Drug stock-outs, even of simple pain medications, are common. There is no access to morphine or pethidine.

Specific palliative care provision and ratings for each organization are given below.

Organizational Capacity Level	Qualifying Criteria for Organizational Capacity Level	Organisation
Level 1 Not Palliative care	<ol style="list-style-type: none"> 1. Relies mainly on community health workers (CHW)/volunteers 2. Includes basic administrative structures 3. Provides supportive care 4. Does not provide basic OI and/or pain assessment and management services 	MAICC NAPHAM NACC COPRED Lusubilo Orphan Care Tutulane AIDS Organisation
Level 2	<ol style="list-style-type: none"> 1. Relies on CHW/volunteers and part-time qualified health professionals 2. Includes basic administrative structure and procedures (for example job descriptions) 3. Provides support and basic clinical services for OI, WHO level 1 pain assessment and management 	Nkhoma Synod Hospital and HBC Malamulo SDA Hospital Ekwendeni CCAP Hospital
Level 3	<ol style="list-style-type: none"> 1. Relies on CHW/volunteers and full-time qualified health professionals 2. Includes managerial and administrative structure and procedures (management, technical and support staff) 3. Relies on multidisciplinary team approach for service delivery 4. Uses protocols for support and clinical services for OI and pain assessment and management 5. Provides support and clinical services for OI and at least WHO level 2 pain assessment and management 6. Manages a basic referral network for provision of essential palliative care components 	
Level 4—Center of Excellence	<ol style="list-style-type: none"> 1. All Above 2. Manage a proactive referral network 3. Provide support and clinical services for OI and WHO level pain assessment and management 4. Provide technical assistance and training to partner organization 5. Recognized palliative care champion 	Lighthouse

Objective 3: To identify the current strength and gaps for palliative care delivery.

The palliative care assessment highlighted the themes of

- training
- volunteer HBC skills (including emotional counseling, spiritual care, physical care and bereavement)
- referral systems
- supervision systems.

These will be discussed for each PACT partner and strengths and gaps identified for palliative care delivery.

- **Training:** As there is currently no palliative care course available in Malawi for HBC providers/volunteers, this gap will be seen reflected in all organizations.

○ **MAICC**

The organization trains its volunteers in HBC but no palliative care training for anyone has been undertaken to date. MAICC has taken the initiative to plan a palliative care training course in conjunction with PACAM, for health care workers working in nearby health facilities.

Strength: Home-based care volunteers have received CHBC training.

Gap: the two health professionals within MAICC have not been trained in palliative care. CHBC volunteers have not been trained in palliative care.

○ **NAPHAM**

This organization offers training to community HBC volunteers but focuses on prevention of positives and condom use. The trainer (nurse) has not received training in palliative care and therefore no volunteers have received any palliative care knowledge.

Gap: there are no palliative care trained health workers or volunteers.

○ **Nkhoma Synod**

Volunteer training is based on the standardised 2 week HBC Ministry of Health curriculum and is undertaken by Umoyo. A one week refresher training is based on locally identified needs. There is a perception that training is strongly focused on nursing. However it appears that volunteers involve themselves more with counselling and supportive care and tend to avoid nursing chores with the patient. Palliative care training was provided for 2 weeks in 2007 by 2 visiting doctors from USA. A link to an interfaith palliative care network has resulted in an allowance for training for health professionals in palliative care and 4 staff members have already been trained at Lighthouse, although 2 of these are now leaving this facility. There is an intention to train some volunteers with the curriculum from Mulanje Hospital but this is still to be discussed with PACAM. There is a perception that shorter and more regular training would be preferable to the current 2 week module which is not supported with any follow-up training and supervision.

Strengths: palliative care training has been provided to 4 health workers. Plans are in place to extend palliative care training to volunteers.

Gaps: staff turnover means that training investment is costly and risky. The staff who have been trained still face implementation challenges, and could benefit from a clinical attachment at another programme. Training and supervision of volunteers is compromised due to lack of palliative care trained health workers.

○ **Lighthouse**

The palliative care training curriculum developed here formed the basis for the national 5 day training now in place and ratified by MoH. Volunteers receive training with the 10 day national HBC training which Lighthouse have adapted to 5 days. Their perception is that shorter training followed by ongoing skills transfer with nurse supervision is most beneficial. Annual refresher training for volunteers is recommended in the National Guidelines but Lighthouse offers this every 6 months. Additional training in HIV counselling and testing is a 3 week course.

Strengths: palliative care training for health professionals is well established and this centre provides the only palliative care training open to health workers from other institutions and organisations across Malawi. Trained health workers are able to transfer palliative care skills to volunteers through mentoring and supervision. Their experience in training has resulted in adaptation of the national curriculum for volunteers and could be used to lobby for required changes.

Gaps: volunteers are not formally trained in palliative care as a national curriculum at that level has yet to be finalized.

○ **NACC**

No palliative care training has been undertaken. Volunteers are trained according to the national HBC curriculum.

Strengths: The nurse at the nearest health centre has received training in palliative care although may have limited application of the skills

Gaps: there are no health workers employed by this organization. Palliative care training for community volunteers is not currently available.

○ **Malamulo**

Training for both health workers and volunteers follows national guidelines. The facility has trained HIV primary supervisors in skills that equip them to act as a mid-point between the volunteers and the health staff. They also distribute contraceptives. No one has yet been trained in palliative care.

Strengths: the mix of health professionals and volunteers would be well placed to create a multi-disciplinary palliative care team

Gaps: the hospital health workers do not have training in palliative care.

○ **COPRED**

Volunteers are trained according to national HBC guidelines. Those interviewed however felt there are gaps in the national curriculum. They suggest changes could be made to the emphasis on statistics, and to focus more on what can be done to relieve pain. Specifically, volunteers could benefit from training in how to assist patients who cannot eat because of a sore mouth. They also suggest volunteers should have better PMTCT training, and know how to advise on breast feeding. This organization considers training *in situ* is preferable to 2 weeks of classroom training, and would like to see the introduction of a shorter formal training (5 days) and more practice and practical sessions.

Strengths: the experience of the organization enables them to suggest how to achieve maximum potential in the volunteers. As a grassroots community organization they present a realistic and pragmatic approach to training issues and appear to avoid unnecessary and irrelevant training packages.

Gaps: there are no health professionals within this organization, No one in the organisation has training or experience in palliative care.

○ **Tutulane**

There has been no palliative care training to date. Volunteers are trained according to the national HBC curriculum in which counseling skills training is perceived by the interviewee as inadequate. Many of their volunteers are illiterate and this causes problems with the current style of training.

Gaps: volunteer training in HBC skills is not adequate. No palliative care training has been undertaken. The health workers at Chitipa District Hospital are not known to have had palliative care training.

- **Ekwendeni CCAP Hospital**

Training of volunteers is according to the national HBC guidelines although they have also received refresher courses in home-based care, in which palliative care has featured. This facility provided training in home-based care for 50 clinicians (nurses and clinical officers) two years ago, to ensure an integrated approach. At the same time 23 clinicians were trained in palliative care by Lighthouse.

Strengths: palliative care training has started to be introduced at volunteer level. A good percentage of clinicians at the facility have received initial training from Lighthouse.

Gaps: all volunteers have not had access to palliative care in the course of their training as this has been introduced at refresher course level. Training of health workers in palliative care has begun but has not been supported by ongoing training or supervision.

- **Lusubilo Orphan Care**

Volunteers identified for HBC training were nominated by the village orphan committees without using selection criteria. This raises concerns about whether the best people were selected for training. Many did not in fact pass the post-training evaluation, and questions were raised in the interview as to the credibility of the training and subsequent skills of the volunteers. Another concern raised was the age of the volunteers selected for training. Many were very old and seemed forgetful, leading to worries that training details may be lost.

Gaps: inappropriate selection criteria for volunteers means that training may not achieve the maximum potential. The health workers employed in their organisation do not have palliative care training.

- **Volunteer HBC skills with special reference to counselling skills, spiritual care, bereavement and physical care capacity**

- **MAICC**

The patient who was interviewed indicated that when he is in pain he “goes to bed, sleeps and cries”. His greatest problems when we interviewed him were his seriously swollen legs from KS, and distended stomach, both of which were causing pain and discomfort. These had not been attended to despite regular visits, possibly because he had not told the volunteer. This raised concerns about the volunteer’s exploratory questioning skills. It was not possible to observe a volunteer at work in the evaluation.

Strengths: the new Care and Support Coordinator appears to have a good understanding of patient care issues and is well placed to improve the skills of the volunteers once she receives training.

Gaps: good counseling skills and the ability to effectively obtain information from patients in a sensitive but active manner appear to be lacking.

- **NAPHAM**

The health worker who was interviewed found it difficult to give examples of emotional and spiritual exploratory questions. She regards bereavement counseling as providing comfort and was unable to suggest how she may find out how the loss has impacted on her client.

This health worker undertakes the training in the community for HBC volunteers, so it is of some concern that those volunteers are not receiving training in counseling skills at the level they will need to effectively help chronically ill patients and their families. The volunteers have care kits but there is a re-supply problem and there are often shortages.

Gaps: good counseling skills are lacking in all areas. Physical care for patients receiving HBC is compromised due to insufficient kit supplies, resulting in constant referrals to health facilities.

○ **Nkhoma**

This facility acknowledges that ART patients do better with HBC than without. However there is a perception that volunteers are not achieving full potential in counseling skills, bereavement issues and spiritual care due to lack of skills. There is no discussion of death and dying, loss or funeral issues with families and those interviewed felt volunteers do not have appropriate training to manage those issues.

Gaps: volunteers are not equipped with skills, even after HBC training, to discuss issues relating to palliative care. Health workers are also not confident in discussing issues of death and dying.

○ **Lighthouse**

This organization provides HBC volunteers with limited kits that contain gloves, condoms and ORS. They are fully supported by nurses who carry kits that include antibiotics and painkillers at all levels including oral morphine. It was not possible to assess counselling skills in this evaluation. Those interviewed however confirmed that little bereavement work is undertaken, with the nurse visiting once as a post-death visit. Volunteers continue to visit the family once a patient has died for 3 or 4 visits as they have developed relationships with the family, but this is considered supportive only.

Strengths: the multi-disciplinary approach of this organization ensures that patients receive good physical care in their homes.

Gaps: palliative care skills that address death and dying are absent despite training in HBC for volunteers and palliative care for health workers. Bereavement counseling rather than simply supportive and social visiting requires attention.

○ **NACC**

The advent of ART has impacted on the work of volunteers with this organization, with few clients apparently now being seriously ill and fewer dying as before. As a result volunteers spend less time visiting clients and usually this is once weekly. While volunteers would have previously spent time 'motivating' seriously ill patients, they tend now to visit without that focus. Both health worker and volunteer who were interviewed were unable to give examples that demonstrate exploration of emotions or spiritual beliefs. The volunteer confirmed he talked of issues of death and dying with patients although the example he gave indicated a preaching style convincing the client that everyone lives and dies. Home-based care kits were donated from the National AIDS commission, but are barely minimal and sometimes cannot be refilled at the health centre. They do not provide medicines. The volunteer interviewed explained his understanding that bereavement support is talking in a religious way to the client. As an example he would say to the bereaved: "You are not the only one this has happened to in the world; it's how God planned it". His approach to exploring the meaning of life and death with his patients would be to encourage them to pray. It was observed that the volunteer's personal beliefs guide his spiritual counseling.

Gaps: skilled counseling and bereavement support require attention. Basic counseling skills appear to be missing such as listening, questioning techniques, and not imposing personal belief systems. Care kits are inadequate, thereby minimizing physical care of the patient in his own home.

○ **Malamulo**

With the integrated approach of this facility there is close linking between the hospital and the HBC volunteers who follow up and monitor treatments and refer patients to hospital. Volunteers also perform chores like bathing, dress wounds and house duties. Care kits are minimal and include gloves and Panadol. Volunteer counselling skills around issues of death and dying are absent. When asked what a volunteer would say to someone who is so ill that they think they will die, we were told they would preach the word of God. The volunteer would also take someone with them to the patient who had been ill and already recovered to convince the patient to think positively about getting better. This raised concerns about confidentiality over and above lack of skills.

Strengths: volunteers should be able to draw on the expertise of health professionals at the hospital rather than refer the patient always to the facility.

Gaps: good counseling skills, especially around spiritual issues and death and dying, are absent.

○ **COPRED**

The care kits used by the volunteers comprise soap, gloves, JIK and Savlon, but no pain killers. Accordingly patients are very often referred to the health facility. It is the experience of this organisation that children are often not informed about their parents' illnesses. The tendency of volunteers would be to break this news to the children if asked to do so by parents, rather than empower parents to tell their own children with the support of the volunteer. Those interviewed confirmed they lack skills in working with children and do not know how to respond to them when difficult topics arise. Although they offer bereavement support this is in the form of prayer and encouragement to the bereaved to be positive.

Strengths: this organization impress as being open to hearing of improved ways to work with terminally ill people and acknowledge the areas in which they are lacking.

Gaps: good counseling skills around issues of death, dying and bereavement are lacking, especially so with children. Due to poor care kits and supervision volunteers are unable to provide adequate physical care at home.

○ **Tutulane AIDS Organisation**

The HBC volunteers with this organization perform a variety of duties including checking how the patient is, washing clothes, cleaning the house, bathing patients and cooking. They have drug boxes in the community for provision of basic drugs. The volunteers provide emotional and spiritual counseling but it was not possible in the evaluation to determine skill levels of counseling.

Strengths: a wide variety of practical chores are undertaken to assist patients in their homes. Simple medications can be administered at home.

Gaps: possible that counseling skills are similar to the other organizations and requiring attention to exploratory emotional and spiritual questioning.

○ **Ekwendeni CCAP Hospital**

Volunteers attached to the programme obtain firewood, pray, help in the garden, and provide physical and moral support. It was not possible to assess counseling skills in the course of the evaluation. A new programme has enabled training of 8 'care givers' who are

family members living in the same house as the patient. The rationale behind this is that trained family members will provide sustainable support while volunteers can only visit regularly. Only very simple home-based care kits are available and to only 50 volunteers.

Strengths: investing training in family members who provide the bulk of care for chronically ill patients will result in a sustainable approach to palliative care.

Gaps: limited care kits means that patients may not be kept comfortable at home and will need to be hospitalized.

- **Lusubilo Orphan Care**

The HBC volunteers undertake home visiting to seriously ill patients without the aid of any medicines and sporadic home based care kits. One volunteer mentioned receiving Panadol, gloves, spirit and Aspirin as a care kit but felt this was inadequate. This is partly due to a lack of funding. Consequently volunteers express their lack of confidence at managing symptoms in the home. Volunteers do not work with children, and interviews exposed a lack of general counseling skills required for palliative care. In particular volunteers are ill equipped to provide bereavement counseling, claiming the way they would do this currently would be to “give reassuring word from the bible that God created us and one day will take our lives so if someone dies let’s hope that God has invited him”.

Gaps: volunteers are lacking good counseling skills, especially to work with children and to provide meaningful emotional, spiritual and bereavement support to families.

- **Referrals/networking/integration with health system**

- **MAICC**

This organization has access to Mponela rural hospital, 2 CHAM hospitals, Dowa district hospital and 4 of the 7 health centres in the district.

Referrals work well from the HBC programme to hospital but not the other way around. When a patient is discharged from hospital to their community the organisation is not notified.

Strengths: existing integration into the mainstream health system and a good relationship with health centres. This organization is notable in its attempts to call a ‘referral meeting’ involving all stakeholders in an attempt to strengthen the system. Although the meeting did not result in an immediate improvement there are strategies now to address the issue.

Gaps: two-way referral and communication system requires continuing improvement. Due to the lack of morphine at HBC level palliative home based care is not possible, resulting in an overload on the hospital system when pain becomes unbearable.

- **NAPHAM**

The organization works closely with the health centres and hospitals in the areas in which they work. All HIV related services are obtained at the health centres and clients are referred regularly. NAPHAM has good links with Lighthouse and the Lilongwe Diocese and networks as necessary with them. There is a referral form that is used when a patient needs to be referred to a health facility for resuscitation or drip rehydration. The hospital writes an update on this form which is returned to the organization.

Strengths: good working relationships with health facilities and other organizations offering similar care. A referral system is in place for information sharing.

Gaps: volunteers are unable to provide interim care to ill patients at home to avoid regular inconvenient trips to health facilities. Due to the lack of morphine at HBC level palliative home

based care is not possible, resulting in an overload on the hospital system when pain becomes unbearable.

- **Nkhoma**

The integrated approach of this hospital-based programme means that referrals by the hospital to the HBC teams are immediate and quickly followed up. There is however no established referral system for patients discharged on morphine from hospital to HBC. There is a referral form for other patients to the HBC team. Every client on ART is referred to HBC and this has achieved excellent results in terms of adherence. Referrals from the HBC team of patients requiring hospitalization or medical care are also easily achieved. The supervising link of nurses who accompany HBC volunteers ensures that referrals are appropriate. Community health programmes provide care for children under the age of 5, family planning, TB and HIV services.

Strengths: an integrated hospital-based HBC system provides an effective way of ensuring the best care possible for patients.

Gaps: the referral system for patients discharged on morphine to HBC is not established. Palliative care provision in the home by volunteers and family members could improve care at home generally and avoid overloading the hospital.

- **Lighthouse**

This organization is based within the grounds of Kamuzu Central Hospital and enjoys close working relationships with this MoH facility. Its integrated approach and multidisciplinary team enables patients to receive palliative care at home with the back-up of hospitalization if required. Referral systems are well established between the VCT clinic, day care ward and HBC teams.

Strengths: a well-integrated service ensures rapid and appropriate 2 way referrals.

- **NACC**

The two health centres of Katuli and Namwera lie within the catchment area of this organization. Within a reasonable distance are also St. Martha Hospital and Nacholi health centre. NACC uses standard government HBC referral forms. They enjoy good relationships with the health centres as evidenced by the positive feedback they receive. They refer too to other services including Total Life Care (an NGO providing farm inputs) and Hallelujah Orphanage who support malnourished children. Clients are identified in the community through relatives asking for help, and referral forms are in place for referring clients to the organization as well as referrals to other facilities.

Strengths: a community based organization that links effectively with mainstream health centres and other health facilities. Relationships have been established with other NGOs.

Gaps: despite good linkages the full range of palliative care services remains unavailable for patients who require them. Due to the lack of morphine at HBC level palliative home based care is not possible, resulting in an overload on the hospital system when pain becomes unbearable.

- **Malamulo**

This integrated hospital-based programme allies its referral system with its supervision system. When volunteers recognize that a patient requires more help than they can provide, this is discussed with the volunteer's supervisor who will then effect a referral to the hospital. The programme works closely with Medecins Sans Frontieres in HBC, PMTCT and HCT programmes. The hospital also enjoys a close relationship with the district health office and provides joint supervision with them. Volunteers are selected by the community.

Strengths: this hospital-based HBC approach has an established 2 way system of referrals to ensure good patient care. Close links are in place with other health services.

Gaps: due to the lack of morphine at HBC level palliative home based care is not possible, resulting in an overload on the hospital system when pain becomes unbearable.

- **COPRED**

HBC volunteers have limited palliative care capacity to manage patients at home and there are regular referrals to the nearest health facilities. Often patients will be taken by ambulance, or if living far away from health services, volunteers will organize transport and usually accompany the patient. As this is a CBO referrals to the organisation are within the community.

Strengths: the community has a sense of ownership of this organization and referrals come from within the community.

Gaps: referrals to health facilities depend on transport availability although ambulances are easily available to those living nearby health facilities. Lack of palliative care provision at home results in overloading of health systems for hospitalization.

- **Tutulane**

A clear referral system is in place between this organization and Chitipa District hospital. The latter refers patients to Tutulane by using the national HBC referral forms. Someone from the hospital sometimes visits the organisation to get feedback on the referrals. However there is no system in place for feedback from the hospital about patients referred by Tutulane. There is some concern that patients are occasionally unable to follow through with referrals at the hospital due to transport problems. Furthermore there is concern about conditions at the hospital: “the hospital is so overcrowded and overwhelmed we don’t know if it is useful to make referrals”. The organization has tried to negotiate for preferential attention for people who have been referred but this has been unsuccessful.

There are other health centres in the area, but they do not have any medical personnel and therefore Tutulane does not refer patients to them. This organisation works well with other CBOs within the villages and a separate referral form is completed for referral to HBC services in the community. Of note is a program called GIPA (Greater Involvement of People living with HIV/AIDS). This support group follows up patients and reports to the health worker at Tutulane.

Strengths: established links with the local hospital, as well as clear referral systems in place for networking with other organizations.

Gaps: lack of feedback system once the patient is hospitalized. An initiative to seek priority of care for seriously ill patients referred by Tutulane has been unsuccessful. Due to the lack of morphine at HBC level palliative home based care is not possible, resulting in an overload on the hospital system when pain becomes unbearable.

- **Ekwendeni CCAP Hospital**

Once a diagnosis of a terminal condition is made at the hospital, the patient is referred for HBC and/or palliative care if they are bedridden, seriously ill, in severe pain and being treated with morphine or diclofenac. The hospital works closely with Livingstonia Synod (LSAP) where there is also a health facility. The two health facilities cover the same area and have established an effective 2 way collaborative referral system. A referral form is completed for HBC services once the patient is discharged from hospital. The form is given to the patient who passes it to the volunteer.

Strengths: an integrated hospital-based system allows for simple referral procedures to ensure care for the patient at home and in hospital. Good linkages with other health facilities have been established.

Gaps: morphine is not always available at the hospital, limiting the possibilities for sustained HBC palliative care when patients are discharged.

- **Lusubilo Orphan Care**

Some patients are referred to Karonga District Hospital which has a home-based care coordinator. Information about the patient is lacking however once referred to hospital. “It’s just a one way communication; we don’t get any feedback when I refer patients to the hospital”.

Most patients receiving HBC are referred to the Lusubilo Orphan Care clinic which is staffed by a nurse and has a supply of drugs. Referrals are also made to a private clinic. The organization covers the cost of this and sometimes a volunteer accompanies the patient. There are no formal systems in place for these referrals, although referral letters are sometimes written, and there is a referral form used when HBC is requested by other organisations.

Strengths: health care is sought for patients when it is recognized that the organization needs support.

Gaps: a lack of 2 way communication about patients causes concerns. Referral mechanisms need to be formalized. Due to the lack of morphine at HBC level palliative home based care is not possible, resulting in an overload on the hospital system when pain becomes unbearable.

- **Supervision, patient load:**

- **MAICC**

There is approximately a ratio of 1 volunteer to 2 patients. A total of 508 volunteers work in pairs and are supervised by only 5 field officers and 2 HBC staff members. Monthly supervision visits are done in each zone with supervisors accompanying volunteers to homes where there are problematic patient histories. There are also quarterly review meetings where volunteers can present concerns but this is not conducive to exploring personal issues. The organization concedes that supervision is a problematic area and is at best a way of providing some support for difficult cases.

Gaps: There is no opportunity for personal and developmental growth for volunteers. Supervision visits are erratic and respond to crises rather than provide an opportunity for true supervision and development.

- **NAPHAM**

The evaluation assessed that an effective supervision system throughout the organization is lacking and the person interviewed feels unsupported in her work. Volunteers are supervised monthly by the nurse who accompanies them on visits to see what they are doing.

Gaps: supervision appears inadequate at all levels. At the volunteer level, supervision visits are primarily policing and a matter of checking up on duties rather than developmentally focused.

- **Nkhoma Synod**

All committees are visited monthly for supervision to check on activities by 2 nurses accompanied by health surveillance assistants (these have basic training in disease surveillance, HBC and immunisation). Volunteers complete a reporting form which has 5 activity categories, but this is still in need of adjustment. This information is used for the

volunteer's monthly report. Volunteer meetings are always in groups meaning that individualised supervision is not possible. On each visit 2 or 3 clients are visited by volunteers and nurse together, so that activities can be observed.

Gaps: supervision primarily focuses on activities according to a check list. The concept of developmental supervision for volunteers to be assisted to achieve their greatest potential is unknown. Personal issues are not encouraged.

○ **Lighthouse**

Supervision at this organization is undertaken by a member of the management team who visits a group of volunteers. By using a checklist the nurse files are checked and random visits to patients are undertaken with the relevant volunteer. The management team that were interviewed were of the opinion that rather than being nervous, the volunteers report that they feel motivated and validated by this approach. It was not possible to interview a volunteer or witness a supervision visit on the evaluation. For personal self developmental supervision a small opportunity arises when the nurse meets the group of volunteers. An individual can make time to be heard then; otherwise supervision and mentoring is always in a group setting.

Gaps: supervision is always in a group setting which may prevent an individual from being able to use supervision opportunities for issues that may impact on the work. The interplay between personal lives and experiences, and volunteering to care for ill people needs to be explored in a skillful manner. There is no supervision training provided to equip supervisors to perform their role.

○ **NACC**

Data provided by the organization shows an extremely high number of 3155 male and 3966 female volunteers, accounting for a total of 7121 volunteers. The number of clients is far less at 4383 (1657 male and 2726 female). The volunteers work in 300 villages in 3 traditional authorities. Supervision is undertaken once and sometimes twice a month by the project supervisor who will contact the volunteer and accompany him to a patient. The supervisor checks the data kept by the volunteer. The volunteer interviewed expressed worries that the demand is too high for the volunteers to meet. The evaluator has serious concerns about these statistics; no effective supervision is possible by the limited numbers of staff for such enormous numbers of volunteers. Most volunteers are presumably untrained, and at a ratio of nearly 2 volunteers for each client it is unlikely that volunteers are stressed by patient load.

Gaps: insufficient capacity for supervision raises concerns for volunteer skill levels.

○ **Malamulo**

Supervision is performed by 4 nurses who visit the volunteers and accompany them on visits once or twice a month. The primary supervisors accompany volunteers once or twice a week with a checklist to see what they are doing. The supervision chain starts with volunteers who are supervised by primary health supervisors who are supervised by a nurse who is supervised by the project coordinator. Each volunteer sees about 15-20 patients.

Strengths: a supervision chain ensures everyone in the system is afforded supervision.

Gaps: supervision is simply a check-listing of activities rather than developing skills.

○ **COPRED**

Volunteers who were interviewed admitted that they sometimes feel sad with their work but they do not let it out or cry. They felt that if they did they would discourage others. Good supervision would provide an opportunity for this kind of self-care that is clearly lacking.

Gaps: supervision as an opportunity to explore personal reactions to situations and develop self-awareness appears to be missing. There is no recognition of the value of developing the skills of individual volunteers, especially in regard to self-awareness and expression of emotions.

○ **Tutulane AIDS Organization**

The 60 trained volunteers visit approximately 300 patients in 2 traditional authorities. There is a system in place whereby every month each volunteer is allocated 3-4 patients which they are individually responsible for. They may visit in pairs or groups but they are individually responsible for those allocated patients. For one person to be responsible for more than 4 patients may compromise quality. The health worker does not receive any field supervision. The director simply “asks me to submit a field report that’s all”. When the health worker supervises volunteers she visits a volunteer twice a month to a patient and observes the volunteer’s patient care e.g. wound dressing. No training has been received for supervisors. Every service that a volunteer provides to patients is written in the patient’s book. The patient keeps these records and notes everything that the volunteer does. These books are used for internal reporting.

Strengths: the reporting system held by the patient is an attempt at transparency and patient empowerment, yet it raises issues of power relationships that require closer consideration. The volunteer/patient ratio appears sensible and effective in terms of capacity and quality.

Gaps: productive supervision beyond checking on activities and physical care of the patient could be improved.

○ **Ekwendeni CCAP Hospital**

The 300 home-based care volunteers visited 763 patients last year. The HBC supervisor has a bicycle to make frequent visits to patients and refers them for palliative care as necessary. There are monthly supervision meetings for the volunteers when difficulties are discussed. The nurse herself is supervised by a senior nurse: “She asks me some questions relating to work and drugs and observes the way I handle a patient and I also submit a monthly report”.

Strengths: a regular supervision system is in place for all levels of workers.

Gaps: supervision is based upon checking activities and performance rather than expanding skills and self-development. Palliative care skills could be transferred through supportive and individualized sessions.

○ **Lusubilo Orphan Care**

In the first quarter of 2008 there were 246 registered patients. By June 2008 this number had risen to 449. HBC volunteers total 108 relating to a ratio of approximately 1:4 volunteers to patients with each patient visited perhaps fortnightly. The volunteers cover a big catchment area and transport is a problem. The organization hopes to reach a volunteer level of 80. Responsibility for quality of service rests with the HIV officer and the field officers. Supervision of volunteers is managed by the HBC coordinator at the district hospital (MoH) as well as the orphanage nurses. Volunteers also meet the village orphan committees who rely on the volunteer reports. A volunteer describes how monthly supervision is done: “A nurse comes to my house and asks me to show her my patients. At the patient she asks me to demonstrate to her what I do while she is observing”. No training in supervision has been given to supervisors.

Gaps: a rigorous and systematic supervision schedule has not been established by the organization. Supervision that is undertaken is more along the lines of a health check up for the patient and a check up on the activities of the volunteer. With supervision training the potential of volunteers could be much greater.

Objective 4: To make practical recommendations for the strengthening of palliative care services among PACT partners.

The evaluation of the 10 PACT partners raised several areas where implementation of palliative care could significantly improve the lives of patients and families, and where a palliative care approach and training could dramatically increase the capacities of volunteers and health workers. These points will be discussed before leading to specific recommendations.

- Due to the current lack of resources to enable patients to die at home, nurses and volunteers commonly perceive that patients prefer to die in hospital as they do not have the resources at home. It was clear from discussion with patients however that they would actually prefer to be cared for in their homes so long as they are pain-free and comfortable. Poverty, lack of food and accommodation are the main problems that currently make dying comfortably at home impossible. Problems arising as a result of their illness were cited as divorce, relationship problems, having to leave the home and a lack of resources. Patients are not asked where they would like to die and patient involvement in care decisions is uncommon even with palliative care nurses. Some interviewees recognized that better counseling could help people to make different choices about place of death. One health worker confirmed that there is very little difference between what she could achieve with a patient at home, and what is done at hospitals, but lack of resources and an inability to obtain the confidence of patients are the main obstacles. Volunteers find poverty one of the most difficult areas to work with, and consequently actively persuade patients to go to hospital where they feel there are more comforts. Another difficult aspect for volunteers which results in pressurizing patients is that they choose not to take their medication because of lack of food. Related to this was the notable scarcity of income generating activities at all sites.
- Counselling skills relating to helping families manage the illness in general, and issues of death, dying, spirituality and bereavement in particular, are at a basic level at most of the organizations. Typically, questions to find out about the impact on the family of the illness were neither probing nor open-ended. Most of those interviewed were unable to give an example of emotional enquiry or spiritual questioning. Spiritual care is overwhelmingly faith-based teaching rather than exploratory questioning. Even at Lighthouse which is considered a centre of excellence, palliative care and the skills associated with the palliative care approach are limited to health workers. Lighthouse acknowledges that “the volunteers are not able to discuss issues of death and dying with patients”. This is partly explained as a cautionary approach as volunteers could be accused of witchcraft coming from the same community as the patients with whom they would discuss issues of death and dying. If this argument is valid, the question then needs to be asked how volunteers can be included in a palliative care team. Currently volunteers mainly attend to practical and social needs, and monitor drug adherence for morphine and ART. Volunteers are reportedly reluctant in some sites to do nursing care (bathing, dressing wounds and touching the client). At Lighthouse it was reported that at times volunteers fail to touch the client and to just be with them. Having identified this trainers and supervisors are focusing on this in follow-up supervision. Given the amount of training that is invested in volunteers, and cognizant of the expressed identified need for further training in various areas of care this issue needs to be debated fully at all

partner sites, and training adapted if necessary. At present it appears that some care for patients is seen as enough care, but in a palliative care context this issue needs to be addressed.

- Children were seldom mentioned or included in any of the programmes that were visited. When questioned about working with sick children, most organizations appear to have only a couple or none registered on their books. Queries concerning including children in a family-centred approach led to a conclusion that children are truly invisible in the families that are assisted by the organizations. Some volunteers acceded that they find it difficult to work with children, and no one who was interviewed was able to assess or manage pain in children with any confidence.
- Pain is often seen in patients along with other distressing symptoms, like wounds that do not heal and was regularly identified as a common problem faced by health workers and volunteers. Apart from Lighthouse and Ekwendeni CCAP Hospital none of the other organisations is able to administer morphine to patients in a home setting. When asked how health workers and volunteers manage intractable pain, the most common response was given as “give Panadol, pray and refer to the nearest health facility”. Despite being unable to provide strong analgesics many respondents felt that pain is well enough controlled as patients sometimes respond to paracetamol or ibuprofen. This perception may be due to ignorance of how pain can be well controlled.
- Few volunteers admit to their work being stressful. This may indicate an unwillingness to admit to what they may consider a failure in their work, but it may also indicate a true lack of pressure of work, and even an indication of superficial involvement with patients. Their main stresses appear to be gaps in transport and medications. Without exception all interviewees expressed a deep enjoyment and satisfaction with their work despite the problems they face.
- None of the organizations has strict criteria for selecting volunteers. Most rely on volunteers being identified within a community process, with all nominated volunteers being accepted. This raises questions about motivations and abilities.
- None of the organizations has equipment to loan patients such as mattresses, bed sheets, urinals, bedpans or sheepskins. Provision of these comfort items would make a difference to patients being comfortable at home, and helping family members feel more confident at maintaining good levels of patient care.
- Volunteers are mainly provided with incentives such as soap and bicycles, but a common complaint at every site was that volunteers require some kind of stipend. All are unemployed and many volunteer to be able to eventually get employment. Training is often seen as an incentive.
- Many patients are known to visit traditional healers. Health workers were open about patients’ perceptions that health professionals would be negative about this, and issues of appearing judgemental and exclusive about treatment need to be addressed.
- The main areas of concern expressed by health workers and volunteers were feeling unsupported in the work. Often people felt left on their own to solve patient problems, including financial difficulties and it was common to hear of volunteers using their own money to help clients. One health worker expressed her frustration at being left alone to find her own solutions: “I would have enjoyed my work if my colleagues supported me and worked hand in hand cooperatively. But what happens most of the time, I have to go up and down to get information instead of people bringing it to my office”. Another complained “my volunteers always present their

problems to me but when I present them to my boss they don't assist me". Lack of transport is a big problem affecting work satisfaction. Many health workers and volunteers talked of the lack of transport for home visits, and no morphine for pain control. One admitted that "deep down they sometimes feel sad with their work but don't let it out or cry. They feel that if they did they would discourage others". There was no apparent attention paid to self-care or care for the carer.

Recommendations

- It would be beneficial for staff in the PACT office to receive training in palliative care in order to increase their technical knowledge and to better help partner organizations determine whether and how they wish to incorporate palliative care into their work, and what this will mean for a HBC programme. Understanding of the relevant PEPFAR indicators and reporting mechanisms in palliative care seems to be an area of concern.
- The entire training approach for HBC in general and palliative care in particular requires revision. Many organisations commented that they would prefer a shorter theoretical training time than the current stipulated 10 days, and would prefer a 5 day training followed by rigorous and effective mentoring and supervision. These suggestions should be seriously considered and discussions held with MoH to decide on a more effective way of ensuring skills transfer to volunteers. PACAM has just begun to coordinate 2-week clinical attachments for health care workers trained in palliative care. This kind of continuing training should be evaluated to guide decisions about training module development.
- Some of the responses used as examples in this report could make effective bases for role plays in training and used effectively to illustrate 'before' and 'after' results of training.
- Supervision is an area identified as in great need of improvement. A move away from a check-list approach towards a developmental and progressive way of working with volunteers is suggested. For this to be effective consideration needs to be given to introducing supervision training and mentoring. This point needs to be raised in Monitoring and Evaluation components in all projects.
- It is imperative to clarify the links and differences between HBC and palliative care. These concepts continue to confuse many of those interviewed and it is essential to establish a clear distinction and relationship so that health workers, volunteers and families are aware of what palliative care can offer that is different to what a good neighbor can provide.
- It is recommended that palliative care should be included in all initial trainings of health workers and volunteers rather than only at refresher level.
- Improved referral systems with CHAM and MoH health facilities need to be developed, and demand for morphine and other essential palliative care drugs clearly expressed. Ongoing advocacy is required for palliative care generally and for safe expansion and accessibility of morphine in particular.
- Improved resources and linkages need to be established with MoH, suppliers of medications and donors to avoid the common stock-outs of drugs at all sites, as well as the recurring re-supply problems with HBC kits.

Conclusion

Interviews with a cross-section of people associated with the 10 PACT partners that claim to provide palliative care highlighted misunderstandings concerning palliative care, particularly in the HBC setting. Training of health workers and volunteers requires reconsideration as observations in the evaluation provided evidence of poor counseling skills, minimal pain assessment and management, and a lack of holistic and multidisciplinary work. The lack of effective supervision systems exacerbates this problem. The existing core of palliative care practitioners in Malawi is well placed to support emergent palliative care HBC programmes and wherever possible, links and networks with established palliative care programmes should be made with PACT partners for mentoring and placements. Ongoing advocacy efforts should yield better morphine availability at health facilities serving PACT partners, which will help make palliative HBC a reality in Malawi.

References and resources

Ministry of Health, National AIDS Commission (NAC) and Palliative Care Association of Malawi (PACAM) (2007). Introduction to Palliative Care. Health Care Workers' Training Manual. (Unpublished).

Wright M. and Clark D. (2006). Hospice and Palliative Care in Africa. Oxford: Oxford University Press.

Appendix I: Questionnaire for HBC Volunteers

APCA evaluation of PACT sub-grantees: Malawi Questionnaire for HBC volunteers

Instructions:

- Explain that we are conducting an interview with PACT sub-grantees to learn how organisations provide treatment, care and support for people living with HIV/AIDS.
- Please ask the person being interviewed to answer as fully as possible all the following questions.
- Assure them that all information will be treated confidentially and ask them to be as specific and detailed as possible.
- Probe more deeply if necessary.
- Allow them to ask further questions if necessary.
- If a question is not relevant, write 'NA' (not applicable).

Date of interview	<input style="width: 100%; height: 100%;" type="text"/>
Location of interview: _____	
Name of organisation: _____	
Name of person interviewed (optional): _____	
Designation: _____	
Name of interviewer: _____	
Starting time of interview:	<input style="width: 100%; height: 100%;" type="text"/>

1. Is your organisation part of a

Government health facility	[]
Private health facility	[]
Faith-based/mission health facility	[]
NGO/CBO	[]
Other	[]
Please describe	

2. Are you required to keep records? If so what happens to these?
(Obtain reports and other relevant data if possible)

3. How many of your clients are taking ART?
 All
 Most
 Few
 None
4. How many of your clients do you estimate stop taking ART once they have started? Why do you think they do this?
 All
 Most
 Few
 None
 Dont know

5. What changes have you experienced in your work since ART has been available to your clients?

6. Please tick the **services** that you currently offer to your clients and their families (if the service is not provided, make a dash across the space). **This is a brief checklist only. There will be space later in the questionnaire for more details.**

Service	Adults 18+	Youth 13-17	Children <12
HIV-testing and Counselling promotion			
Adherence to ARTs counselling & support			
Emotional support			
Directly Observed Treatment (DOTs)			
PLWHA Support groups			
Providing food			
Nutrition education			
Help with the gardening			
Symptom management incl. local remedies			
OI treatment			
Provide Bactrim			

prophylaxis			
Pain assessment			
Pain management			
Provide opioids for pain management			
Provide pain medication other than opioids			
Home-based care supplies			
Sweeping			
Cooking			
Washing clothes			
Collecting firewood			
Fetching water			
Provide mattresses, bedpans, wheelchairs, etc.			
Bereavement Support			
Physical support (e.g. Bed bath, dressings)			
Transportation support			
Spiritual support/prayer			
Microfinance/IGA			

7. Have you heard of the term palliative care?

Yes

No

If yes, what do you understand by the term palliative care?

8. Please list 3 activities that you would carry out as part of palliative care as a home based care volunteer

1.

2.

3.

9. How many of your clients died in the last year?

10. Have you ever received training in palliative care?

Yes

No

If yes, please provide examples of training topics

Course	Topics	Length of training – dates (may include refresher course)

11. Who conducted the training? Please list the organisation(s) that trained you.

12. How do you assess pain in your **adult** patients? You can tick more than one
(Do not read out. Wait for their response)

- Hands
- Body charts/point to part of the body
- Scale of 0-10
- From what the patient says
- Clinical signs
- Make a list of what I see and what the patient complains of Ask the patient what is wrong None of the above Other (please specify)

13. What are the most common symptoms you see in your adult patients? (Eg. diarrhoea, constipation, nausea and vomiting, skin conditions, shortness of breath and cough, fatigue, insomnia)

14. Are you confident that you can treat these symptoms?

Yes

No

Explain

15. How do you assess pain in your **child** patients?

From what the child says

Clinical signs

Smiley faces

Interviewing parent

Interviewing siblings

I don't know how to assess pain in children

Other, please specify

16. What are the most common symptoms you see in your child patient? (Eg. diarrhoea, constipation, nausea and vomiting, skin conditions, shortness of breath and cough, fatigue, insomnia)

17. Are you confident that you can treat these symptoms?

Yes

No

Explain

18. Have you heard of the WHO analgesic ladder?

Yes

No

If yes, please describe what you understand by it and how you use it

19. What do you do if your patient is in pain? (**Do not read out.** Wait for response)

Give the patient medication according to the WHO analgesic ladder

Give Panadol

Do not know what to do

Pray

Refer to my supervisor

Refer to nearest health facility

Refer to traditional healer

Other, please describe

20. Do you have all you need in your care kits to attend to all your patients' health problems?

Yes

No

Sometimes

Explain

21. Do you talk about the following issues with your patients? (Read out the list)

What is wrong with them

Whether they will get better or not

Death and dying

Disclosure of HIV status

Sexuality needs

The future

Funeral planning

- Bereavement
- Care for the spouse
- Care for the children
- The extended family

22. Please give one example of a question you use to discuss how the patient and family are feeling about how HIV affects their lives.

23. Are you confident that you are able to attend to your patients' emotional needs?

Yes

No

If no, please describe

24. Please give one example of what you say to someone whose loved one has died (the bereaved)?

25. Do you ask the patient and the family about their beliefs about the meaning of life and death?

Yes

No

Sometimes

Please explain

26. Please give one example of a question you use to discuss the meaning of life and death with your patients and families

27. How are clients referred to you? Is there a referral form?

28. Where do you refer your clients if you feel you can do no more to help? Describe how you do that. Is there a referral form?

29. Do you know of other agencies or organisations in this area that give care and support to sick people and their families in the community?

Yes

No

If yes, please list

30. How often do you receive information about your client when you are not seeing them, such as how their illness is going, death, recovery?

- Often
- Never
- Sometimes
- Please describe

31. Who supervises you in your work?

32. How often do you receive supervision?

33. Can you describe what happens when you have supervision?

34. Does this work make you stressed?

- Yes
- No

35. Do any of the following provide support when you are stressed by this work?

- Your supervisor
- Your colleagues
- Your spouse
- Your children
- Friends
- Church and/or other groups

32. What do they do that helps?

33. Do you think this is enough?

- Yes
- No

If no, please describe what you think you need.

34. What gives you the biggest satisfaction in your job and why? Please describe

35. What gives you the least satisfaction and why? Please describe

36. What would help to make your work more satisfying?

Thank-you

Ending time of interview:

Total time of interview:

**Appendix 2: Questionnaire for Health Workers
APCA evaluation of PACT sub-grantees: Malawi
Questionnaire for:**

Health service providers (doctors, nurses, pharmacists, social workers)

Instructions:

- Explain that we are conducting an interview with PACT sub-grantees to learn how organisations provide treatment, care and support for people living with HIV/AIDS.
- Please ask the person being interviewed to answer as fully as possible all the following questions.
- Assure them that all information will be treated confidentially and ask them to be as specific and detailed as possible.
- Probe more deeply if necessary.
- Allow them to ask further questions if necessary.
- If a question is not relevant, write 'NA' (not applicable).

Date of interview	
Location of interview: _____	
Name of organisation: _____	
Name of person interviewed (optional): _____	
Designation: _____	
Name of interviewer: _____	
Starting time of interview:	

36. Is your organisation part of a
- | | |
|-------------------------------------|-----|
| Government health facility | [] |
| Private health facility | [] |
| Faith-based/mission health facility | [] |
| NGO/CBO | [] |
| Other | [] |
| Please describe | |

37. Do you offer VCT at your health facility or in the neighbouring vicinity?

- Yes
- No
38. Do you offer Provider-initiated counselling and testing through other health services at your health facility as well?
- Yes
- No
39. Do you have a PMTCT programme at your health facility or in the neighbouring vicinity?
- Yes
- No
40. Are patients with HIV/AIDS given ART at your facility?
- Yes
- No
41. Are you involved in HIV/AIDS prevention or risk reduction practices? Please describe how.

42. Have you heard the term palliative care?
- Yes
- No
- If yes, what do you understand by the term palliative care?

43. Please list 3 activities that you would carry out as part of palliative care at your institution

- 1.
- 2.
- 3.

44. How many patients died under your care in the last month?

45. Have you received any training in palliative care?

- Yes
- No

If yes, please provide details of training topics

Course	Topics	Length of training – dates Refresher course?	Trainer/ Organisation

46. How do you assess physical pain in adults? (Do not read out list; wait for response)

- Smiles/faces
- Hands
- Body charts/point to the body
- 0-10
- From what the patient says
- Clinical signs
- I don't know how to assess pain
- Other (please describe)

47. How do you assess pain in children? (Do not read out list; wait for response)

- From what the child says
- Clinical signs
- Interviewing parent/guardian/carer
- Interviewing siblings
- I don't know how to assess pain in children
- Other (please describe)

48. Do you use any guides to treat pain?

- Yes Which?
- No

49. Have you heard of the WHO analgesic ladder?

- Yes
- No

If yes, please describe what you understand by it and how you use it

50. What drugs do you use to manage **neuropathic** pain?

51. How available are these drugs in your facility?

- always available
- some stock-outs
- never available.

52. What drugs do you use to manage **mild** pain?

53. How available are these drugs in your facility?

- always available
- some stock-outs
- never available.

54. What drugs do you use to manage **moderate** pain?

55. How available are these drugs in your facility?

- always available
- some stock-outs
- never available.

56. What drugs do you use to manage **severe** pain?

57. How available are these drugs in your facility?

- always available
- some stock-outs
- never available.

58. Do you have any fears or concerns about the use of opioids?

Yes

No

If yes, please describe

59. What is your understanding of total pain? Please describe

60. In your opinion do you think enough is being done in your facility to manage patients' pain

Yes

No

Sometimes

Please expand

61. What symptoms do you commonly see in your patients? You can tick as many as you like. (Do not read out this list; wait for responses.)

Pain

Diarrhoea

Constipation

Nausea/vomiting

Weight loss/anorexia

Fatigue

Insomnia

Skin conditions

Depression

Confusion

Other (describe)

25. How often do you feel confident that you have treated symptoms in the best way possible for the patient?

Always

Sometimes

Never

Add more information if you like

26. Do you ever ask the patient whether they have visited a traditional healer?

Yes

No

What is a common response?

27. Do you talk about the following issues with your patients?

- Their diagnosis
- Their prognosis
- Death and dying
- HIV/AIDS
- Cancer
- Sex
- The future
- Funeral planning
- Bereavement
- Care for the spouse
- Care for the children
- The extended family
- Their beliefs about the meaning of life and death
- Please expand

28. Please give an example of a question you would use to find out how HIV/AIDS is impacting on the lives of a family.

29. Please give an example of a question you would use to discuss the meaning of life and death with your patients.

30. Have others in your facility received any palliative care training?

- Yes
- No
- If yes, please list

31. Do you know of other agencies or organisations that give care and support to seriously sick people and their families in the community? Yes

No

If yes, please provide information in the box below

Name of agency or organisation	Run by (e.g. Government, NGO etc)	Service that is provided

32. Describe how referrals are done from your facility to the community or to other services.

33. How often do you receive information about your patient from other sources, such as progression of illness, death, recovery?

- Never
- Often

Occasionally
 34. How satisfactory are your referral systems (inward and outward)?

35. Who supervises you in your work? How often?

36. If you are supervised, can you describe what happens when your supervisor visits?

37. When you supervise a home based care volunteer can you describe what happens? How often do you offer supervision?

38. Have you received training in how to supervise home based care volunteers?

Yes By whom?
 No

39. Do you feel you receive enough support in your work?

Yes
 No
 Please explain

40. Why do you do this work?

41. Do you enjoy the work that you do?

Yes
 No
 Sometimes

42. What would help you to enjoy your work more?

Thank-you

Ending time of interview:

Total time of interview:

Appendix 4: Questionnaire for PLWHA
APCA evaluation of PACT sub-grantees: Malawi

Questionnaire for PLWHAs

Instructions:

- Explain to the person being interviewed why s/he is being interviewed in a short concise manner.
- Explain that it is part of a study to improve care and support for people living with HIV/AIDS.
- Please ask the person being interviewed to answer as fully as possible all the following questions
- Assure them that all information will be treated confidentially and ask them to be as specific and detailed as possible.
- Probe more deeply if necessary.
- If a question is not relevant, write 'NA' (not applicable).

Date of interview	
Location of interview: _____	
Name of person interviewed (optional): _____	
Name of interviewer: _____	
Starting time of interview:	

Age:
Male/female:

1. What is your nearest health facility?

Government Provincial Hospital	[]
Government District Hospital	[]
Private Hospital	[]
Mission Hospital	[]
Rural Health Centre/clinic	[]
Dispensary	[]
Other (please describe)	
2. What is the distance from the health facility to your home?
3. When you need assistance at the health facility how do you get there?

4. Are you still able to care for yourself?

Yes

Sometimes

No

If no, what do you have difficulty with? (Please specify)

5. Where do you prefer to receive your care?

At my home

In hospital

I am too sick to mind

Other (please specify)

6. If you need looking after, who is doing this?

My spouse

My child(ren)

Whoever is free to help

My relative(s)

My neighbour

The church

Home based care volunteer

7. What is your greatest problem? Mark 1 as your most important problem and number from there in order of importance)

Problem	Prioritise	Has this been addressed? If yes, how
Pain		
Nausea and vomiting		
Itching skin		
Shortness of breath and cough		
Diarrhoea		
Constipation		
Mobility		
No appetite and weight loss		
The way I look		
Fear/worry		
Grief		
No drugs		
Can't look after myself		
Lack of food		
Lack of money		
Fear of dying		
Other (please specify)		

8. When you are in pain or your symptoms make life hard, what happens?

9. Who asks you how you would like to manage your illness?
10. Up to now, has anyone explained what is happening to you with your illness?
 Yes
 No
 If yes, please explain your understanding
11. Has anyone outside your family checked with you how you are feeling about how your illness is affecting your life?
 Yes
 No
 If yes, please explain
12. Has anyone outside your family asked you how you feel about life and death since you have been ill?
 Yes
 No
 If yes, please explain how this happened
13. Have you sought the services of a traditional healer?
 Yes
 No
14. If yes, how has the traditional healer been of help?
 Has helped the pain
 Has managed diarrhoea
 Has managed nausea/vomiting
 Has helped with appetite
 Has not been any help
 Other (please specify)
15. Is home-based care available in your area?
 Yes
 No
 Don't know
16. If yes, what services are offered? (You can mark more than one)
 Nursing care
 Counselling
 Give drugs
 Give bedding

- Give money
- Praying
- Give food parcels
- Teaching family carers
- Health education
- Orphan support
- Other (please specify)

17. If your condition were to change for the worse, where would you prefer to go for care and help and why?

- To the traditional healer
- To my neighbours
- To the health facility
- To stay where I am
- To my rural home
- Other (please specify)

18. How has this sickness affected the family?

- Termination of employment
- Problems with relationships
- Fear
- Divorce
- Lack of resources
- Children's welfare
- Move from marital home to family home
- Other (please specify)

19. How has the HBC organisation been able to help with these problems?

20. Has your family been able to benefit from any income generation project?

- Yes
- No Why not?

21. What difference has the project made to your family's ability to look after itself financially?

22. What HIV/AIDS health services are available in your area?

- TB programme
- PMTCT
- VCT
- Longer term counselling
- Other (please specify)

23. How are you helped to make decisions about ART? (whether to start treatment, how to adhere, side-effects etc)

24. In your opinion what makes it hard for people to access community based health services?

- Lack of child care
- Transportation
- Stigma
- Work schedule
- Conflict with hours/days that the services are offered
- Cost services
- Gender imbalance
- Unsupportive family/partner
- Domestic violence
- Alcohol and drug misuse
- Religious or cultural beliefs
- Lack of awareness of services
- Other (please specify)

Thank you. Ask if there are any questions.

Ending time of the interview:

Appendix 3: Questionnaire for HBC Manager/Senior
APCA evaluation of PACT sub-grantees: Malawi
Questionnaire for HBC Manager/Senior

Instructions:

- Explain that we are conducting an interview with PACT sub-grantees to learn how organisations provide treatment, care and support for people living with HIV/AIDS.
- Please ask the person being interviewed to answer as fully as possible all the following questions.
- Assure them that all information will be treated confidentially and ask them to be as specific and detailed as possible.
- Probe more deeply if necessary.
- Allow them to ask further questions if necessary.
- If a question is not relevant, write 'NA' (not applicable).

Date of interview:	<div style="border: 1px solid black; width: 100%; height: 40px; display: flex; align-items: center; justify-content: center;"> / / dd/mm/yyyy </div>
Region: _____	
District: _____	
Name of Organization _____	
Name of person interviewed (optional): _____	
Designation: _____	
Name of interviewer: _____	
Starting time of interview:	<div style="border: 1px solid black; width: 100%; height: 20px;"></div>
End of time for interview:	<div style="border: 1px solid black; width: 100%; height: 20px;"></div>

Staff:

1. How many staff do you have in your programme?

2. What is the skills mix of staff (doctors, pharmacists, nurses, etc) at your organization?

Access

3. Do you have any criteria for patients with life-limiting illnesses who want to access your service?

4. Are you able to accept all the patients that wish to access your service?

Yes	[]
No	[]
If no, please explain.	

5. Are there any costs to patients?

Yes	[]
No	[]
If yes, please explain.	

6. What are the approximate percentages of patients accessing your service?

Please estimate

 - Cancer patients
 - HIV patients
 - TB patients
 - Other

7. How many patients are allocated to each volunteer?

8. Do you have a system whereby people/organizations/volunteers refer to your service and if so how does it work?

9. Do you have a system whereby your staff refer patients to other services e.g. support groups, and if so how does it work?

10. Please describe the links between your organization and the public health facilities?

Components of care



11. What home-based care services does your program provide?

12. How does your program define palliative care?

13. Is your organization providing palliative care?

Yes

No

If yes, please proceed to the next question.

If no, please proceed to question 21.

14. Please explain what your program considers to be the essential elements of palliative care.

15. Based on the essential elements described above, can you list any barriers or challenges and solutions that make it hard for your organization to implement palliative care?

Essential Element	Barrier or Challenge	Solution

16. What medicines do you provide to your patients?

ARVs

Yes

No

CTX prophylaxis

Yes

No

Treatment for OI's

Yes

No



- Analgesics
- Yes []
- No []
- Medication for symptom control
- Yes []
- No []
- If yes, please specify.

17. What problems do you have with the supply of medicines?

18. Are there essential medications that you do not have that you need?

19. Are you aware of any national practice standards and guidelines for palliative care? If so, please list.

20. Are you aware of a national policy that manages opioid use in Malawi? If so how does this impact on your organization's ability to use morphine for pain relief?

21. Do you provide the preventive care package (e.g. cotrimoxazole, bed nets, safe water, VCT) for patients?

Yes []

No []

If no, please explain.

Multi-professionalism and training

22. How many community volunteers work with your organisation?



23. Describe how supervision is undertaken with the volunteers

24. What palliative care training do healthcare providers and volunteers receive in your organisation?

25. What value does/could palliative care add to the home based care service that you provide?

26. What do volunteers and staff find most difficult that extra training could address?

27. If you could add one extra service to your programme, what would you like to provide?

This is the end of the interview – Thank you for your assistance. Do you have anything to add at this time?
(Please record any additional information on back of sheet)